Unrepresented Residents How Can Bioethics Improve Compliance and Risk Management?

AHLA Long-Term Care and the Law 2021

Christine J. Wilson, RN, JD, MS, HEC-C Thaddeus Mason Pope, JD, PhD, HEC-C Christine J. Wilson RN, JD, MS, HEC-C Tyler & Wilson, LLP 5455 Wilshire Blvd., Suite 1812 Los Angeles, CA 90036 CJW@tyler-law.com

Thaddeus Mason Pope JD, PhD, HEC-C Mitchell Hamline School of Law Saint Paul, Minnesota 55105 Thaddeus.Pope@mitchellhamline.edu

2

Importance of bioethics for post-acute & long-term care

H,





Value of Bioethics

1

Η.

How bioethics committees and clinical ethics consultants advance risk management and compliance objectives in PA-LTC

H.

Key Guidance

New laws, regulations, and policy statements on decision making for **incapacitated residents without surrogates** (unrepresented or unbefriended residents)

Role of Bioethics

10

8

How bioethics protects resident rights, especially regarding informed consent and end-of-life treatment

Surrogates & Proxies

H.

7

How bioethics helps identify surrogate decision makers and resolve surrogate conflicts without the time and expense of guardianship or conservatorship

H

Η.

H,

14

Implementation **Strategies**

13

15

Helpful pointers and considerations for establishing a bioethics committee or for contracting for clinical ethics consultation services



Bioethics is rare in PA-LTC



18

H.



Geriatric Nursing Volume 25 Number 6

Ethics Committees in Long-Term Care Facilities

Mildred O. Hogstel, PhD, RN, Linda C. Curry, PhD, RN, Charles A. Walker, PhD, RN, and Paulette G. Burns, PhD, RN

19



Table 5. Availability of mechanisms to address

Mechanism	Hospital %
Institutional Ethics Committee	96.0
Institutional Risk Management	92.0
Officer	
Consultation with Peers	96.0
Consultation or Decision by	72.0
Chief Medical Officer	
Obtain a Guardian	100.0
23 2/10/2021	

17 facilitiesrespondedto survey

20

JOURNAL OF AGING & SOCIAL POLICY https://doi.org/10.1080/08959420.2020.1851433



H.

Check for updates

H,

Unrepresented Adults Face Adverse Healthcare Consequences: The Role of Guardians, Public Guardianship Reform, and Alternative Policy Solutions

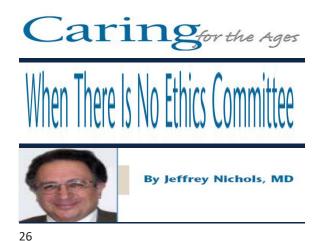
Casey C. Catlin^a, Heather L. Connors^b, Pamela B. Teaster^c, Erica Wood^d, Zachary S. Sager^e, and Jennifer Moye^e

22

Table 5. Availability of mechanisms to address issues with unrepres

Mechanism	Hospital %	Long term Care %
Institutional Ethics Committee	96.0	60.0
Institutional Risk Management Officer	92.0	51.4
Consultation with Peers	96.0	76.5
Consultation or Decision by Chief Medical Officer	72.0	84.8

Other assessments



25

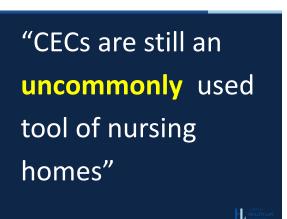
Ethics support in institutional elderly care: a review of the literature

Sandra van der Dam,¹ Bert Molewijk,^{2,3} Guy A M Widdershoven,³ Tineke A Abma³

To cite: van der Dam S, Molewijk B, Widdershoven GAM, *et al.* J Med Ethics 2014;40: 625–631.

H.

27



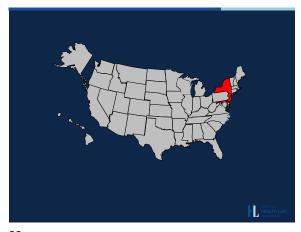
28

CEC prevalence varies geographically

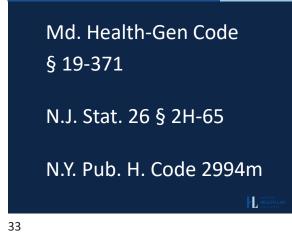


ł,





32



Flexibility in how fulfill mandate

H,

34

PA-LTC committee may function
(1) Solely at that . . . institution
(2) Jointly with a hospital advisory committee
(3) Jointly with . . . committee representing no more than 30 other . . . institutions.



L

Regional Ethics Committees New Jersey Long-Term Care Ombudsman

1-877-582-6995 Guidance. Support. Advocacy.

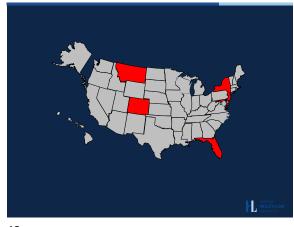
37



In addition to statutory mandates

38





40

We'll come back to those roles



H

H,







THE MARYLAND HEALTHCARE ETHICS COMMITTEE NETWORK

			AMERICAN
	46 2/10/2021	L1	HEALTH LAW
46			



Bioethics still rare in PAC

48

H.

H,



Does your client have a bioethics committee?

50

Is it your own or shared?

(with H or other PA-LTC?

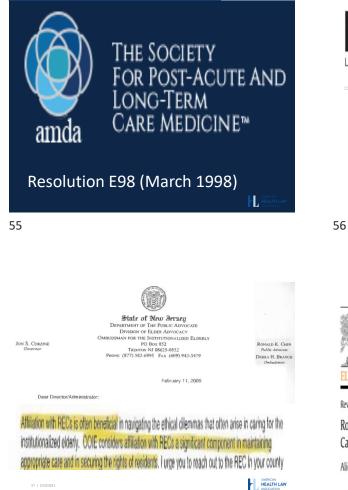
H.

What **benefits** does your HEC provide?

51



Value for PA-LTC recognized over 20 years ago



57

Provider LONG TERM & POST-ACUTE CARE

Bioethics in Post-Acute and Long Term Care

A special interdisciplinary committee can provide guidance and support for difficult clinical decisions providers and families may face.

FEBRUARY 2019

Karl Steinberg, MD, CMD



JAMDA journal homepage: www.jamda.com

JAMDA 21 (2020) 1852-1861

Review Article

Role of a Clinical Ethics Committee in Residential Aged Long-Term 1 Constant Care Settings: A Systematic Review

HEALTH LAW

Alice L. Holmes^a, Lyndal Bugeja PhD^{a,b}, Joseph E. Ibrahim PhD^{C,*}

58

"The benefits of CECs . . . include

- Support for professionals and families in decision making
- Encouraging moral behavior
- Quality improvement
- Reduction in litigation
- Multidisciplinary consideration of ethical issues

Extrapolate research from hospital setting – where there is more research

Η,

Outcomes of Ethics Consultations in Adult ICUs: A Systematic Review and Meta-Analysis

Au, Selena S. MD, FRCPC, MSc¹; Couillard, Philippe MD, FRCPC^{1,2}; Roze des Ordons, Amanda MD, FRCPC, MMEd^{1,3}; Fiest, Kirsten M. PhD^{1,4,5,6}; Lorenzetti, Dianne L. PhD⁴; Jette, Nathalie MD, FRCPC, MSc²

Critical Care Medicine: February 1, 2018 - Volume Online First - Issue - p doi: 10.1097/CCM.00000000002999

61



Meta-review looked at 16 studies 1988 to 2015

Assessed **outcomes** after clinical ethics consultations in the ICU

62



Consensus more often achieved

Less litigation

H,

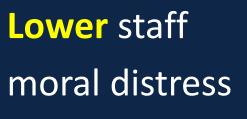
H.

If litigation, courts defer to CEC

Lower

resource utilization

67



H,

H.

H.

68

70

That's ICU where most bioethics consults go

69

There are some PA-LTC studies

show <mark>same</mark> benefits

Caring Sciences

EMPIRICAL STUDIES

doi: 10.1111/scs.12213

H.

74

78

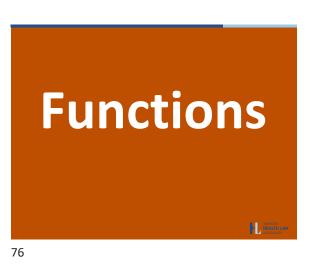
Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

Georg Bollig MD, MAS (PhD Candidate, Consultant)^{1,2,3}, Gerda Schmidt RN, MAS (Ward Manager, Nursing Manager Representative)⁴, Jan Henrik Rosland MD, PhD (Professor, Director, Chief Physician)^{1,2,5} and Andreas Heller PhD, MA (Professor)⁶

"lead to **consent** on acceptable decisions . . . **agreement** acceptable for all involved parties"

73

Let's move to more concrete examples



Education Policies Consults

75

H

H,

Case consult "main" function

H,

H.

Typically prospective

Sometimes retrospective

ssues

Let's focus on the case consult role of the CEC

82

80

What does a PA-LTC bioethics committee do?

79

Η.

H,

H,

Resolve conflicts

Navigate uncertainty

H.

About what?

85



Everyday ethics Ordinary healthcare End of Life Surrogates

88

90

86



Sex Noncompliance Racist requests

18 CARING FOR THE AGES



MEDICAL ETHICS By Elaine Healy, MD, FACE, CMD Intimacy and Dementia in Long-Term Care: Time for a Revisit

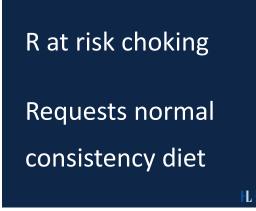
"When a nonresident spouse or family member **objects** to a developing sexual relationship"

91

Optimal clinical care vs. resident rights

92

L

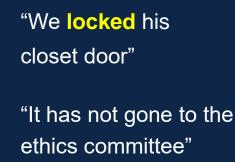




Department of Health & Hum Centers for Medicare & Medic			Printed: 02/06/2021 Form Approved OMB No. 0938-0391	
STATEMENT OF DEFICIENCIES AND PLAN OF CORRECTION	(XI) PROVIDER/SUPPLIER/CLIA IDENTIFICATION NUMBER: 325104	(X2) MULTIPLE CONSTRUCTION A. Building B. Wing	(X3) DATE SURVEY COMPLETED	
NAME OF PROVIDER OR SUPPLIER NM Behavioral Health Institute at Las Vegas(the)		STREET ADDRESS, CITY, STATE, ZIP CODE 3695 Hot Springs Boulevard Las Vegas, NM 87701		
For information on the nursing home's	For information on the nursing home's plan to correct this deficiency, please contact the nursing home or the state survey agency.			
(X4) ID PREFIX TAG	(X4) ID PREFIX TAG SUMMARY STATEMENT OF DEFICIENCIES (Each deficiency must be preceded by full regulatory or LSC identifying information)			
F 0550	Honor the resident's right to a dignified existence, self-determination, communication, and to exercise his or her rights.			

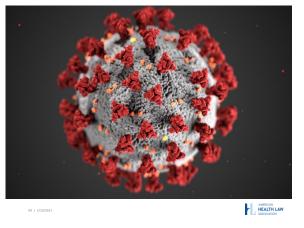


94





Covert medication Coercion/restraints Lack of time



99

"Limited, rationed, or nonexistent supplies and resources ... have forced ... ethical decisions regarding who does and does not receive testing, medication, a bed ... other required care."

Source: PYA

100

98

"ethics committee . . . help balance those decisions; evaluate resources, staffing, supply and equipment rationing . . ." Source: PYA



H.

H,

Advance directives

POLST

103

Completing

Interpreting

Withholding withdrawing treatment

105

Other refusals Antibiotics Etc.

H,

H,



106

104

Table 1. Percentage of Respondents Reporting That Ethical Dilemmas With Respect to the Following Issues Occur at Their Facilities (N = 93)

Issues	n (%)
Assessing residents' decision-making	
capacity	71 (79)
Do not resuscitate decisions	70 (78)
Do not hospitalize decisions	70 (77)
Tube feeding issues	67 (74)
Implementing advance directives	63 (70)
Ascertaining resident health care	. ,
preferences	60 (68)
Identifying surrogate decision-makers	53 (59)
Withholding/withdrawing life sustaining	. ,
treatments	44 (48)
and professional expertise. (J Am Med Dir Assoc 2005;	
6: 68–75)	

HEALTH LAW

H,

Conflicting evidence of R wishes AD

Surrogate

H,

109



111

Care forward.

HEALTH LAW

More controversial **VSED** MAID H,



Conflicting evidence

of R wishes

POLST

Surrogate

112

110



HEALTH LAW

Where?

» Oregon Death with Dignity Act

2019 Data Summary

2019

116 | 2/10/2021

116

115

Patient died at			
Home (patient, family or friend)	177	(94.1)	
Assisted living or foster care facility	5	(2.7)	
Nursing home	4	(2.1)	
Hospital	0	(0.0)	
Hospice facility	1	(0.5)	
Other	1	(0.5)	
	H	AMERICAN HEALTH LAW	

H

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CALIFORNIA END OF LIFE OPTION ACT 2019 DATA REPORT



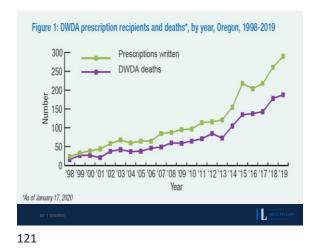
ALTH LAW

L

Patient died at			
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	Assisted living or foster care facility	5	(2.7)
	Nursing home	4	(2.1)
	Hospital	0	(0.0)
	Hospice facility	1	(0.5)
	Other	1	(0.5)
			AMERICAN HEALTH LAW ASSOCIATION

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Location Where Aid-in-Dying Drugs were Ingested	N	(%)
Private Home	357	(88.1)
Assisted-Living Residence	29	(7.2)
Nursina Home	12	(3.0)
In-patient Hospice Residence	4	(1.0)
Acute Care Hospital	1	(0.2)
Other	2	(0.5)
120 2/ta/2023	H	AMERICAN HEALTH LAW ASSOCIATION





122

Policy & procedures H

123



124

Voluntarily Stopping Eating & Drinking



H,

Physiologically able to take food & fluid by mouth

Intent death from dehydration

129

127





128

start of VSED.

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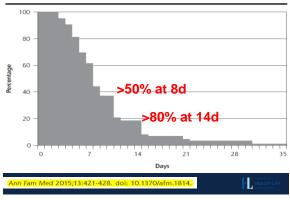
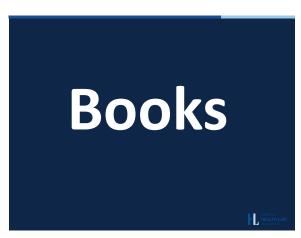
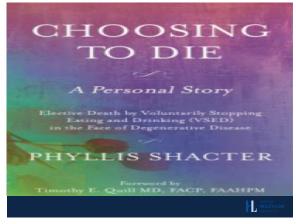
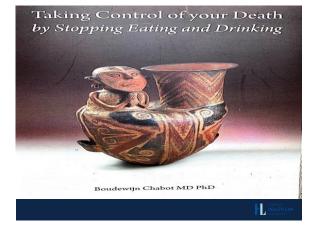


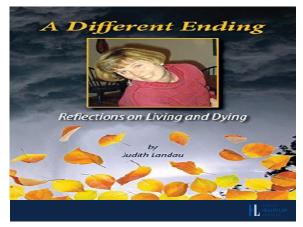
Figure 1. Cumulative survival curve for duration until death after





















Objective evidence

patient experience

H,

140

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

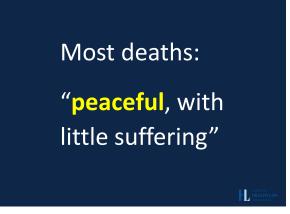
Linda Ganzini, M.D., M.P.H., Elizabeth R. Goy, Ph.D., Lois L. Miller, Ph.D., R.N., Theresa A. Harvath, R.N., Ph.D., Ann Jackson, M.B.A., and Molly A. Delorit, B.A.

141



142

H,





Even though MAID available, **"almost twice"** chose VSED JAMA Internal Medicine | Special Communication | HEALTH CARE POLICY AND LAW Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness— Clinical, Ethical, and Legal Aspects

Timothy E. Quill, MD; Linda Ganzini, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD

JAMA Internal Medicine	January 2018	Volume 178, Number 1	123	
				ASSOCIATION
146				

145





H,

SPECIAL ARTICLE: PALLIATIVE PRACTICE POINTERS

Voluntary Stopping Eating and Drinking

John W. Wax, MD, Amy W. An, MD, Nicole Kosier, MD, and Timothy E. Quill, MD







Nutrition and Hydration at the End of Life

Effective Date:	2017
Status:	Revised Position Statement
Written by:	ANA Center for Ethics and Human Rights
Adopted by:	ANA Board of Directors

LAW

150

H



148



American Medical Women's Association

H.

JOURNAL OF PALLIATIVE MEDICINE Volume 20, Number 1, 2017 Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2016.0290 **Position Statement**

H,

International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide













Staff unsure may or must honor

That's VSED

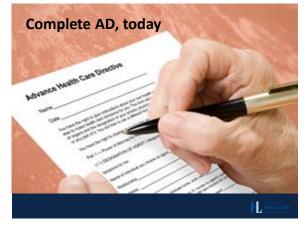
patient with capacity refuses food & fluid

157

158

H.





160



At a **point** Pt specifies



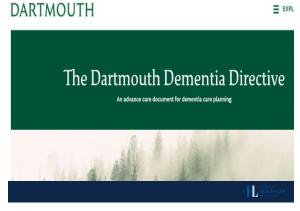


164



ABOUT THE ADVANCE DIRECTIVE FOR **RECEIVING ORAL FOOD AND FLUIDS IN DEMENTIA**

165



166



Introduction to our Supplemental **Advance Directive** For Dementia

H.



168

The Society For Post-Acute And LONG-TERM amda Care Medicine

HEALTH LAW

Focus on needs of current self

Not wishes of prior self

169

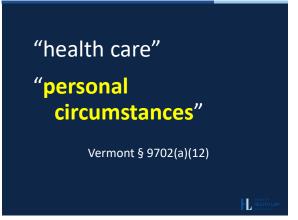


170

H



171



172

"services to assist in activities of daily living"

Vermont §§ 9702(a)(5), 9701(12)

ALTH LAW



H

1. Is AD clear

- 2. AD apply **now**
- Has Pt revoked by current request

H.

H.

H,



When the R lacks decision making capacity Identify surrogate

178

Who <mark>best</mark> knows and cares about the R

Support surrogate

When making tough decisions

H.

175

Surrogate problems

181



182

H,

H,

Conflict among surrogates

Daughter A v. Daughter B

183



HEALTH LAW

"Bad" surrogates

Not what patient wanted

H,

184

inted: 02/06/2021 Department of Health & Human Services Form Approved OMB No. 0938-0391 Centers for Medicare & Medicaid Services (X3) DATE SURVEY COMPLETED STATEMENT OF DEFICIENCIES (XI) PROVIDER/SUPPLIER/CLIA (X2) MULTIPLE CONSTRUCTION AND PLAN OF CORRECTION IDENTIFICATION NUMBER: A. Building 335228 B. Wing STREET ADDRESS, CITY, STATE, ZIP CODE NAME OF PROVIDER OR SUPPLIER 159 163 Front Street - Box 765 Binghamton, NY 13902 Bridgewater Center for Rehab & Nursing L L C For information on the nursing home's plan to correct this deficiency, please contact the nursing home or the state survey agency (X4) ID PREFIX TAG SUMMARY STATEMENT OF DEFICIENCIES (Each deficiency must be preceded by full regulatory or LSC identifying information) Honor the resident's right to a safe, clean, comfortable and homelike environment, including but not limited to receiving treatment and supports for daly liking safely. F 0584 Level of Harm - Minimal harm or potential for actual harm "NOTE- TERMS IN BRACKETS HAVE BEEN EDITED TO PROTECT CONFIDENTIALITY" HEALTH LAW

No available surrogate



188

H,

H,

Increasingly common situation

Patient needs treatment

H,

H,

190

192



No capacity No surrogate

189

H,

H,

Patient cannot consent

Nobody else to consent

194

196



"unrepresented"

"adult orphan"

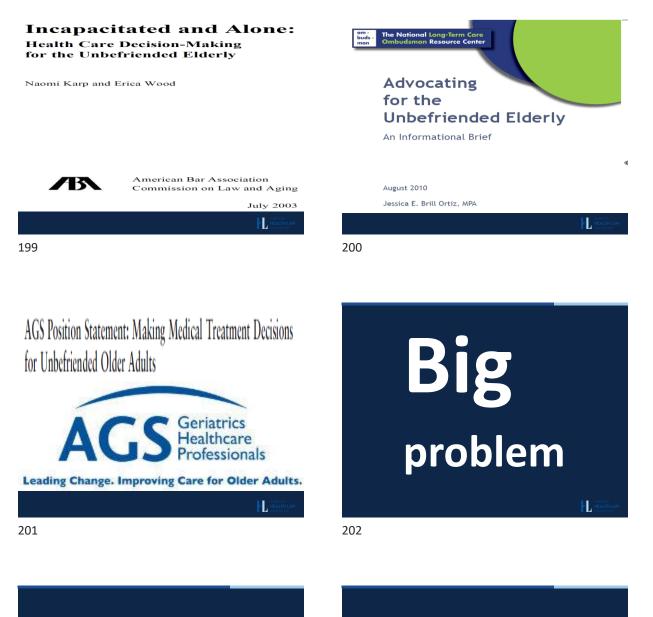
Patient w/o proxy

Unbefriended

"unbefriended"

Most prevalent

H,



3 - 4 %

U.S. nursing home population

Temporarily

unrepresented

204

H

H,

Not just big, but

Growing problem

AMERICAN HEALTH LAW ASSOCIATION

205



207

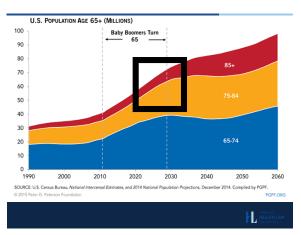


ARP Public Policy Institute **10,000,000 boomers live alone** The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers

210

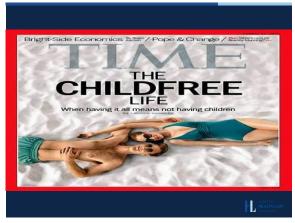
4 key factors

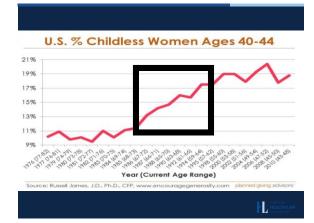
206















H.

H.

Able but unwilling

No **contact** (e.g. LGBT, homeless, criminal)

218

H.

H,

H.



219

217

SDM lacks capacity

220

We have many unrepresented

What's the problem

H.

H,

H,

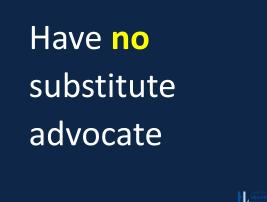
Risks &

Harms

Cannot advocate for self

HEALTH LAW

223



225

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives AGS Ethics Committee

"highly vulnerable"

"most vulnerable"

226

224

GUARDIANSHIP FOR VULNERABLE ADULTS IN NORTH DAKOTA: RECOMMENDATIONS REGARDING UNMET NEEDS, STATUTORY EFFICACY, AND COST EFFECTIVENESS

WINSOR C. SCHMIDT*

"unimaginably helpless"

Problem

228

H,

Nobody to authorize treatment



230

H,





Journal of Aging & Social Policy

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wasp20

Unrepresented Adults Face Adverse Healthcare Consequences: The Role of Guardians, Public Guardianship Reform, and Alternative Policy Solutions

Casey C. Catlin , Heather L. Connors , Pamela B. Teaster , Erica Wood , Zachary S. Sager & Jennifer Moye

232



1

234

H,

Reluctant to act without consent

Wait **Burger**

236

H,

H,

Until emergency

(implied consent)

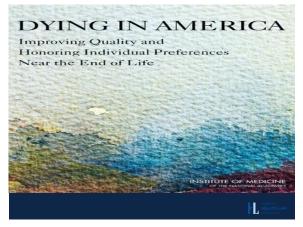
237

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238





Ethically "troublesome . . . wait until . . . condition worsens into an emergency"



242

H.

H.

H,

Overtreatment Fear liability Fear regulatory

H,

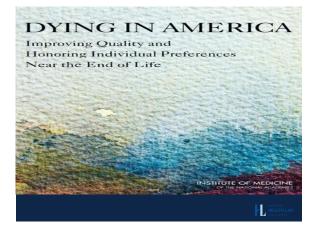
sanctions

244

Treat aggressively



Burdensome Unw<u>anted</u>



248

H,

H.

"compromises . . . consideration of patient preferences or best interests" Takeaway

250



Need a consent mechanism

H.

247

H,

Who decides?

253



CEC Solo Oversight & vetting

Variability

256

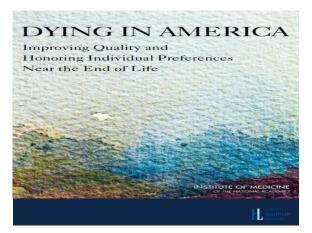
254

Solo clinician Most common approach

H

H,





260

"Having a single health professional make unilateral decisions . . ."

"ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency."

262

H,



Bias & COI unchecked

H,

264

Less carefully considered



266

H,

HEALTH LAW

265

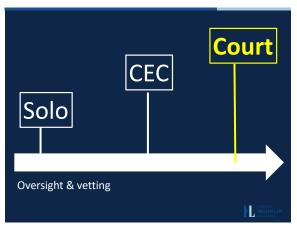


Based on record review and staff interview, the facility failed to ensure that Resident (R)#53 had a legal surrogate to exercise her resident's rights. The facility was aware that R#53 did not have a family member or responsible party and failed to take steps to obtain a legal surrogate.

H,

H,



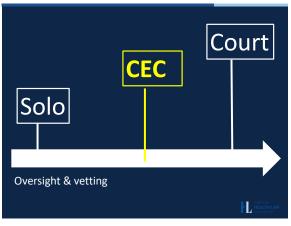


268

Slow, tough getting public guardian



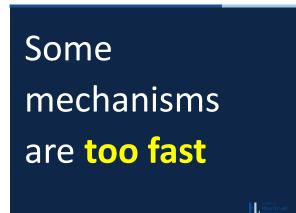
271



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274

Some mechanisms are too slow



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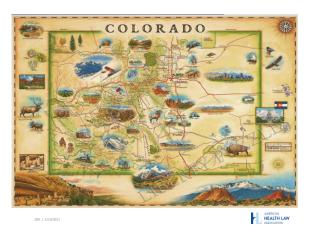
277

"An attending health care provider may designate another willing physician, advanced practice registered nurse, or physician assistant to make health care treatment decisions as a patient's proxy decisionmaker"

278

"consulted with and obtained a consensus on the proxy designation with the **medical ethics committee** of the health care facility where the patient is receiving care"

TENNESSEE



280

H

H,

"designated physician may make health care decisions .
.. consults with and obtains the recommendations of an institution's ethics mechanism"





284



Even without a statute like this

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AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

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JAGS 65:14-15, 2017

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"Decision-making pathways for unbefriended older adults must have adequate safeguards."

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"external entity such as an **ethics committee** . . . review treatment options and to consent to the proposed treatment decision"

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU

An Official American Thoracic Society/American Geriatrics Society Policy Statement

3 Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Cederquist, Andrew B. Cohen, Erin S. DeMartino, David M. Godfrey, Paula Goodman-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Peinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thomton, Mark R. Wicchar, Eric W. Widera, and Douglas B. White; on behalf of the American Thoracic Society and American Geriatrics Society

S OFFICIAL POLICY STATEMENT WAS APPROVED BY THE AMERICAN THORAGE SOCIETY FEBRUARY 2020 AND THE AMERICAN GERIATRICS SOCIETY JANUARY 2021

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Manage decision-making for unrepresented patients using input from a diverse interprofessional, multidisciplinary committee rather than ad hoc by treating clinicians;

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Sometimes required

(by statute or regulation)

Widely recommended

(by professional societies)

Whether delegated a role or not

Useful

(in solving ethical issues)

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The Ethics Committee in the SNF: Where to begin?

Step one: RESEARCH

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Recommended Reading #1: (detailed info in handout)

Beauchamp and Childress "Principles of Biomedical Ethics" (paperback)

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Recommended Reading #2: (detailed info in handout)

Post and Blustein "Handbook for Health Care Ethics Committees" (paperback) HEALSODLA

Recommended Reading #3: (detailed info in handout)

AMDA 2006 White Paper : The Role of a facility Ethics Commtee in Decision-Making at the End of life

https://paltc.org/amda-white-papers-and-resolutionposition-statements/role-facility-ethics-committeedecision-making

HEAI301

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Recommended Reading #4: (handout)

Karl Steinberg, MD, CMD "Bioethics in Post-Acute and Long Term Care" Provider Magazine Feb 2019

https://paltc.org/amda-white-papers-and-resolutionposition-statements/role-facility-ethics-committeedecision-making

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Finding qualified people to help:

Local hospital bioethics committee --Even if they can't help directly, they may be able to make a referral

Independent bioethicists---(ASBH certification commission may be a useful source) https://asbh.org/certification/hcec-certification

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Next step: Define what your committee will do

Education Policy Review Case Studies

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Next step: Define what your committee will do

Decisions Recommendations (based upon ethically acceptable alternatives)

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Essential Committee Members

Medical Director Director of Nursing

Lawyers?

counsel

Individual with background/experience/education in bioethics

Optional/helpful but

should not be

regular facility

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Law can inform ethics but is not ethics

Other Potential Committee Members

2nd MD (not subject patient's attending)

Community Member (confidentiality

Licensed Nurse(s) (RN/LVN/LPN)

Other health care disciplines

compliance required)

Social Worker

Clergy/Chaplain

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Formal clinical case consultation? Not for a general SNF ethics committee Formal clinical case consultation service may be available – evaluate contractual and legal issues.

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How big? What feels right? Start small

Subcommittees may be useful.

NEXT STEP:

Get to work!

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Ethics Related Policy Review

Institutional policy

Next Step:

Co-operative effort:

members/Legal

Administration/Initial

End of life care, Patient rights, Confidentiality, Healthcare decision making Resource allocation

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Case Review: Published case studies (at first)

Current and retrospective in-house cases

Education:

Committee Members Facility Staff Outreach

.

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And finally:

Maintain member engagement and enthusiasm!

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Additionally: chris@elderethics.net www.communityhealthcareethics.org

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